Children with Complex Medical Needs (CCMN) Workgroup
Meeting Notes
January 24, 2012

Date: Tuesday, January 24, 2012
Time: 10:00 a.m. to 12:00 noon
Where: **Springfield**
3rd Floor Prescott Bloom Video Conference Room
201 S. Grand Avenue East
Chicago
7th Floor Video Conference Room
401 S. Clinton Street
Attendees:

Chicago: Dr. Rishi Agrawal, Children's Memorial Hospital and LaRabida Children's Hospital**; Carrie Alani,** Maryville Children's Healthcare Ctr, Chicago**; Jeanette Badrov,** Healthcare and Family Services (HFS)**; Gail Briggs,** Clinical Director, HCI**; Susan Cullinan,** Vice President Loving Care Agency**; Jill Fraggos,** Children's Memorial Hospital**; Christopher Gange,** HFS**; Deborah Grisko**, President and CEO, Almost Home; **Julie Hamos**, Director, (HFS); **Tom Jerkovitz,** Director, DSCC**; Kathleen Lenzmeier**, Branch Director, Loving Care Agency; **Robyn Nardone**, HFS; **Kathy Stegman**, Director of Nursing Almost Home Kids; **Margaret Storey,** Children's Memorial Hospital Family Advisory Board and Public Policy Committee; **Karen Ward,** Equip for Equality (EFE)**; and Brenda Wolfe,** President and CEO, LaRabida Childrens' Hospital.

Springfield: Beth Albert, Anchor Home Health Care; **Steve Bradley,** Division of Specialized Care for Children (DSCC); **Gerri Clark**, DSCC; **Theresa Eagleson**, HFS; **Barb Ginder,** HFS; **Pat Law,** HFS; **Karen Moredock,** Department of Children and Family Services (DCFS)**; Kristin Murphy,** Department of Human Services, Division of Rehabilitation Services**; Jan Sensel**, Anchor Home Health Care; and **Dr. Tim Vega**, Medical Director OSF Health Management.

Telephone: Karen Burde, Parent; **Stephanie Altman**, Health & Disability Advocates

The meeting started at 10:05 a.m. After introductions, the meeting notes from the December 15, 2011 meeting were approved by the group.

Discussion Topics:

1) Update on the Solicitation for Care Coordination Entities and Managed Care Community Networks for Seniors and Adults with Disabilities

The solicitation was released on January 23, 2012. The intent is for providers to organize new and creative ways of providing care for adults with complex medical needs. It is envisioned that the children's solicitation will look similar. The solicitation can be accessed at: Solicitation for Care Coordination Entities and Managed Care Community Networks for Seniors and Adults with Disabilities (pdf)

Comments included:

- The Care Coordination web site provider match maker function is useful to find other providers
- Concern that the RFP references elderly and adults with disabilities (SSI eligible) and that disability and complex needs are not synonymous. It was explained that the federal Medicaid eligibility groups require adults with disabilities to meet SSI eligibility to be eligible for Categorical Medical benefits, where children and seniors do not.

2) Unprecedented budget for 2013

Director Hamos shared that the budget talks in the spring legislative session will focus on Medicaid and pensions. The 2012 budget was underfunded by the legislature by $1.5B. Although the temporary higher federal match allowed bill payments to get caught up by July 1, 2011, the budget shortfall for this year has created a $2B shortfall. Medicaid expenditures have been growing at a rate of 5 percent plus. Rising costs have been attributed to more people served and not an increase in the per member per month costs. For example, more adults have lost employment and health insurance.

There will be pressure this year to not renew the waiver and make this program only eligible to Medicaid eligible children. There may also be pressure to reduce the 300 percent eligibility for children to the minimum allowed under the Maintenance of Effort requirement. Subsequently, the best approach to keeping the program is to impose a cost share.

3) Family Cost Share and Income Caps

Further discussion focused on the approaches to a plan for implementing a family cost share. Director Hamos provided a brief overview of the impact of a 5 percent cost share. For example a family of four at 1000 percent of FPL would have an income of around $225,000/year. A five percent cost share would be approximately $11,250/year. The cost share approach is unlikely to produce significant revenue, but is a philosophical approach showing an effort for participants to contribute toward care and share in the cost when their incomes are above the Medicaid eligibility limits. Director Hamos also indicated that a provider has approached the Department regarding serving ventilator children in a residential setting where costs may be more economical than one to one in home services as delivered currently. Data analysis has shown that home based services are not always less expensive than residential services. No decisions on who would collect the cost share have been made. Further discussion included the following comments.

Participant and Family Feedback

- New Jersey lowered the FPL to 133% of FPL
- Age of majority is 19 years of age (age when child could become eligible for Medicaid as an adult on his/her own case), while the current children's waiver serves children up to age 21
- Child care costs for most families average $12,000 to $15,000/year which is not an expense to families in the waiver
- Cost sharing should be reasonable and not boil down to numbers and dollars
- Consequences of eliminating the waiver are unknown and children could end up costing more if hospitalized
- Health insurance companies need to be responsible for more of the care as almost universally, private duty nursing is not paid through insurance but should be if medically indicated
- There is a risk to the state if families who pay cost share drop insurance, or if families are forced to quit jobs
- The adjusted gross income and other deductions should be considered in establishing a cost share amount
- Need to look at parental share across community and institutional settings, not just in home services
- One parent indicated she could provide a list of out of pocket costs of around $4,500/year, or $550/month. She would be willing to pay a cost share, but would want all expenses to be considered, preferring not to pay over $30/month to participate.

Follow-up:

- Dr. Agrawal will share cost share plans in other states

- Families will assist in helping to make the case for cost sharing with legislators

4) Performance Outcomes

Performance outcomes were shared from the January 23, 2012 Solicitation for Care Coordination Entities and Managed Care Community Networks for Seniors and Adults with Disabilities. The final Performance Outcomes may be accessed at the link above under Appendix A and B. Other Performance Measure specifications can be accessed at:

Performance Measure Specifications for the Care Coordination Program (pdf)

Performance measures from the voluntary Managed Care contract for children were also shared. The contract may be accessed at: http://www.hfs.illinois.gov/assets/mco.pdf

Theresa Eagleson HFS Medicaid Administrator explained that there are two sets of outcomes for the January 23, 2012 solicitation. One set collected on everyone based on persons served and the second set was linked to pay for performance (P4P), or a share in savings. The first 10 percent of cost savings is automatically shared, with the remaining 40 percent distributed in 10 percent increments in four P4P areas: 1) access to member's assigned primary care physician, 2) follow-up with a provider within 30 days after an initial behavioral health diagnosis, 3) medication therapy management. Medication review of all enrollees taking more than five prescription medications and 4) a proposed measure offered by the entity and approved by HFS. Ms. Eagleson reinforced that risk adjustment will be used in analyzing outcomes.

Participant and Family Feedback

- Suggest adopting CHIPRA measures
- Need to define the populations that the outcomes will apply to
- Need to define success – cost savings, length of stay reductions, etc., as success for the state may be different than success for families
- Need to consider outcomes desired by families and start with input from families – outcomes should be fueled by the plans of care
- Need to define what is important, what to measure and how to measure it
- Establish a focus group to design the structure

This triggered further discussion on the different populations: well child, those who receive home based nursing care and others who do not but have multiple chronic conditions. The definitions for the three populations have not been defined, but the care coordination of the in-home services group as proposed in the last meeting would be provided by DSCC and those with multiple chronic conditions would be covered under the children's Care Coordination solicitation to be issued this spring. For the children receiving in-home services, there will be two levels of assessment, 1) eligibility and if eligible 2)a further review to determine risk, care plan development and care coordination levels. DSCC shared that they have developed some process outcomes that they will share with the group.

In summary, the intent of measuring outcomes has two goals, one to measure the progress of individual Care Coordination Entities (CCEs) and 2) to compare across entities. The latter would assist in establishing best practices and to apply to the entire population.

The group suggested that the next meeting would focus on Performance Outcomes through a focus group approach.

5) New Jersey Nurse Delegation Pilot

Susan Cullinan, Vice President, Loving Care Agency/Links2Care from New Jersey shared recent experiences in providing in-home services to children in New Jersey. This state worked closely with nursing agencies and families to create specialized training for unlicensed nursing agency staff through a nurse delegation process. The nursing association was on board, the pilot was a success, but New Jersey decided to move to a Medicaid Block grant and lowered its eligibility from 200 percent of the FPL to 133 percent. In the pilot, nurse aides were specially trained for certain care such as g-tubes and tracheotomy care. Susan will provide more information on the pilot.

Participant and Family Feedback

- Need to address what we need to do to keep children out of institutions
- Medically necessary is the cornerstone to establishing the need for services
- Need to develop an infrastructure that includes telemedicine, real time access to licensed staff to support using non-licensed staff safely

Next Meeting is scheduled as follows:

Meeting #7: Friday, February 10, 10 a.m. to 12 noon.
The meeting will be held at the same locations as previous meetings.
Agenda: Focus Group on Performance Outcomes

The meeting was adjourned at 11:50 a.m.

Requested and other Helpful Links:

Children with Complex Needs Web home page:
http://hfs.illinois.gov/ccmn/overview.html

Voluntary Managed Care contract for children:
http://www.hfs.illinois.gov/assets/mco.pdf

Managed Care web site:
http://www.hfs.illinois.gov/managedcare/

Solicitation and Performance Measures for Adult Solicitation for Care Coordination issued 1/23/12.
General Information:
http://www2.illinois.gov/hfs/PublicInvolvement/cc/Pages/default.aspx

Solicitation and Performance Measures

Solicitation for Care Coordination Entities and Managed Care Community Networks for Seniors and Adults with Disabilities (pdf) , or

http://www2.illinois.gov/hfs/PublicInvolvement/cc/Documents/Innovations%20Solicitation.pdf

- Performance Measure Specifications for the Care Coordination Program (pdf) , or

  http://www2.illinois.gov/hfs/PublicInvolvement/cc/Documents/Performance.pdf

Link for submitting recommendations or information under: Share Your Comments on the Home Page of the CCMN web site:
http://www2.illinois.gov/hfs/PublicInvolvement/ccmn/Pages/Comments.aspx